

Stephanie Billiel
Marlborough, CT
Re: S.B. 200
Insurance and Real Estate Committee
March 6, 2014

FTR

Hi. My name is Stephanie Billiel. I'm here today to speak in support of Senate Bill 200 to expand coverage of medical food for people with Eosinophilic Gastrointestinal Disorders, also known as EGID.

EGID is a genetic disease, and several of my family members are affected. My husband has a mild form. He's lucky that his symptoms are controlled with daily medication. My sister-in-law avoids a few foods to control her EGID but is still able to have a nutritious diet of "normal" foods available in the grocery store. As is the case with most EGID patients, they do not need medical food. They would not be considered when calculating the financial impact of this bill. My older son, Caleb, on the other hand, has a very severe case. He cannot eat "regular" food without becoming extremely ill. He is absolutely dependent on his medical food for nutrition. EGID is a rare disease, and even among EGID patients, a case as severe as his is quite rare.

Let me tell you a little about Caleb. He was born weighing 9 pounds, 7 ounces and measuring 22 inches long. He was a big boy, and he stayed that way - until he started to eat solid foods. Once he started solids, he became increasingly ill with vomiting up to several times a day, alternating diarrhea and constipation, choking episodes, a chronic cough, difficulty swallowing, and dysfunction of his GI tract that caused an obstruction and bleeding in his bowel. As he lost weight, his development regressed, and he went from speaking in sentences to using single words. He didn't have energy to play and spent day after day lying on the couch in a fog of pain and fatigue. My big boy was literally starving to death.

As we struggled to help Caleb, the medical bills piled up with the doctor appointments, extensive medical tests, hospital visits, and emergency medical interventions. As his condition deteriorated, Caleb had 4 emergency department visits and 2 admissions in just a few weeks' time. Finally, he became so ill that he was admitted to the hospital for 8 days. He had stopped eating and drinking and was given a feeding tube. The gastroenterologist treating Caleb in the hospital diagnosed EGID and ordered Neocate Junior, a type of medical food. Caleb's condition quickly improved. In the past 3 years since Caleb's diagnosis, he has not needed a single emergency department visit thanks to the preventative care provided by medical food.

Perhaps you're asking yourself what it will cost to expand medical food coverage. If so, you're asking the wrong question. You should be much more concerned about the cost of NOT covering medical food for EGIDs. Medical food is preventative care, and withholding it from people with severe EGID causes very expensive health complications. Just look at my son's story. In just a few WEEKS of managing the complications from an untreated EGID flare, our insurance paid out more than they would have by covering his medical food for several YEARS. *Preventative care makes financial sense.* Not only is covering medical food the right thing to do; it benefits everyone involved - the families affected, the insurance companies, and the State. Thank you for your time. Are there any questions?